Billing Code 4165-15

DEPARTMENT OF HEALTH AND HUMAN SERVICES

Health Resources and Services Administration

Agency Information Collection Activities: Submission to OMB for Review and Approval; Public Comment Request

AGENCY: Health Resources and Services Administration, HHS.

ACTION: Notice.

SUMMARY: In compliance with section 3507(a)(1)(D) of the Paperwork Reduction Act of 1995, the Health Resources and Services Administration (HRSA) has submitted an Information Collection Request (ICR) to the Office of Management and Budget (OMB) for review and approval. Comments submitted during the first public review of this ICR will be provided to OMB. OMB will accept further comments from the public during the review and approval period.

DATES: Comments on this ICR should be received no later than [**INSERT DATE 30 DAYS AFTER DATE OF PUBLICATION IN THE FEDERAL REGISTER**].

ADDRESSES: Submit your comments, including the ICR Title, to the desk officer for HRSA, either by email to *OIRA_submission@omb.eop.gov* or by fax to 202-395-5806.

FOR FURTHER INFORMATION CONTACT: To request a copy of the clearance requests submitted to OMB for review, email the HRSA Information Collection Clearance Officer at *paperwork@hrsa.gov* or call (301) 443-1984.

SUPPLEMENTARY INFORMATION:

Information Collection Request Title: Sickle Cell Disease Treatment Demonstration Program—Quality Improvement Data Collection.

Abstract: In response to the growing need for resources and coordination of resources devoted to sickle cell disease and other hemoglobinopathies, the United States Congress, under Section 712 of the American Jobs Creation Act of 2004 (Pub. L. 108–357) (42 U.S.C. 300b–1 note), authorized a demonstration program for the prevention and treatment of sickle cell disease (SCD) to be administered by HRSA's Maternal and Child Health Bureau (MCHB) in the U.S. Department of Health and Human Services. The program is known as the *Sickle Cell Disease Treatment Demonstration Program* (SCDTDP). The SCDTDP is designed to improve access to services for individuals with sickle cell disease, improve and expand patient and provider education, and improve and expand the continuity and coordination of service delivery for individuals with sickle cell disease and sickle cell trait. The specific aims for the program are threefold: (1) increase the number of providers treating persons with sickle cell disease, (2) increase the number of providers using evidence-based treatments in sickle cell disease, such as prescribing hydroxyurea, and (3) increase the number of providers knowledgeable about treating sickle cell disease and the number of sickle cell patients that are seen by providers knowledgeable about sickle cell disease.

To achieve the goals and objectives of the program, the SCDTDP uses quality improvement (QI) methods in a collective impact model which supports cross-sector collaboration for achieving measurable effects on major social issues. The collective impact model requires shared measurement which facilitates tracking progress in a standardized method to promote learning and enhance continuous improvement.

Need and Proposed Use of the Information: The purpose of the proposed data collection strategy is to implement a system to monitor the progress of MCHB-funded activities in improving care

and health outcomes for individuals living with sickle cell disease/trait and meeting the goals of the SCDTDP. Each regional grantee site will be asked to report on a core set of evidence-based measures related to healthcare utilization among individuals with sickle cell disease and the quality of care of the SCD population.

The data collected for the SCDTDP will consist of administrative medical claims data collected from State Medicaid Programs and Medicaid Managed Care Organizations that administer Medicaid on behalf of states. The data is collected either for or by State Medicaid offices for delivery of services subject to Medicaid reimbursement.

The data collection strategy will provide an effective and efficient mechanism to do the following: (1) assess the improvements in access to care for sickle cell patients provided by activities in the SCDTDP; (2) collect, coordinate, and distribute data, best practices, and findings from regional grantee sites to drive improvement on quality measures; (3) refine a common model protocol regarding the prevention and treatment of sickle cell disease; (4) examine/address barriers that individuals and families living with sickle cell disease face when accessing quality health care and health education; (5) evaluate the grantees' performance in meeting the objectives of the SCDTDP; and (6) provide HRSA and Congress with information on the overall progress of the program.

Likely Respondents: Four regional grantee sites funded by HRSA under the SCDTDP will be the respondents for this data collection activity and submit responses gathered from State Medicaid Offices and State Medicaid Managed Care Organizations.

Burden Statement: Burden in this context means the time expended by persons to generate, maintain, retain, disclose or provide the information requested. This includes the time needed to review instructions; to develop, acquire, install and utilize technology and systems for the

purpose of collecting, validating and verifying information, processing and maintaining information, and disclosing and providing information; to train personnel and to be able to respond to a collection of information; to search data sources; to complete and review the collection of information; and to transmit or otherwise disclose the information. The total annual burden hours estimated for this ICR are summarized in the table below.

Total Estimated Annualized Burden - Hours

Form Name	Number of Respondents	Number of Responses per Respondent	Total Responses	Average Burden per Response (in hours)	Total Burden Hours
SCDTDP Data form	4	Range:16–80	Range:64–320	Range:4–6	Range:256–1920
Total	4		Range:64–320		Range:256–1920

Jason E. Bennett

Director, Division of the Executive Secretariat

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